

Public consultation on the Commission's Europe's Beating Cancer Plan (Online Questionnaire)

Fields marked with * are mandatory.

Introduction

Cancer concerns all European citizens. 40% of us are likely to be affected at some stage in our life and we all know someone who developed the disease. This is why the President of the European Commission announced [Europe's Beating Cancer Plan](#) to be carried forward by the Commission, under the stewardship of the [Commissioner for Health and Food Safety](#).

Europe's fight against cancer is ongoing ([link](#)). But beating cancer requires everyone's involvement. The Commission wants to place European citizens at the centre of this plan. This is why we want to hear your views as we embark on this journey. Whether you are a concerned citizen, a patient or one of his/her relatives, a healthcare worker, a researcher, an employee in the pharmaceutical sector, or a policy maker, we want to hear from you. Share your experience. Tell us where you think Europe should focus its efforts.

We see the cancer problem as three-fold. First, cancer can cause huge suffering to individuals and their families. The citizen, and patient and his/her immediate family is the starting point and epicentre of Europe's Beating Cancer Plan. The second element is the burden that cancer imposes on society as a whole, stretching health systems. The third dimension is the significant inequalities that exist across Europe in terms of access to high-quality cancer-related services. Access to screening programmes varies significantly throughout Europe. And once diagnosed, patients don't always get access to the treatment that might make a vital difference for them.

With an estimated 40% of cancers being attributed to avoidable causes, we need to do better when it comes to cancer prevention. And as we get better at ensuring people survive cancer, our societies also need to do better at helping survivors with the problems they face subsequently. Therefore, the Commission intends to design the plan to cover the entire cycle of the disease. Actions should span all steps of the disease, including prevention, early diagnosis, treatment, and the social dimension of cancer (encompassing life after cancer, carers and palliative care). We published a roadmap describing this approach under this [LINK](#). Please let us know if you think we have missed something important, be it in terms of problems, objectives, or areas of EU action to explore.

Drawing on your input, the Commission will go on to complement this initial public consultation with further targeted interactions with specific stakeholder groups.

The contributions to this public consultation are not considered to relate to your own personal health situation but may relate to the health experience or situation of family and/or friends.

Thank you for helping us shape the European Cancer Plan!

About you

* Language of my contribution

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- Gaelic
- German
- Greek
- Hungarian
- Italian
- Latvian
- Lithuanian
- Maltese
- Polish
- Portuguese
- Romanian
- Slovak
- Slovenian
- Spanish
- Swedish

* I am giving my contribution as

- Academic/research institution
- Business association
- Company/business organisation
- Consumer organisation
- EU citizen
- Environmental organisation
- Non-EU citizen
- Non-governmental organisation (NGO)
- Public authority
- Trade union
- Other

* First name

Mattia

* Surname

Ceracchi

* Email (this won't be published)

ceracchi@i-com.it

Gender

- Male
 Female

Age

- 14 or less
 between 15 and 24
 between 25 and 39
 between 40 and 54
 between 55 and 64
 65 or more

Highest degree obtained

- Basic education
 Secondary education
 Vocational training
 University degree

* Organisation name

255 character(s) maximum

I-Com - Institute for Competitiveness

Postal address of your organisation

Piazza dei Santi Apostoli 66 - 00187 Rome

* Country of origin

Please add your country of origin, or that of your organisation.

- | | | | |
|--------------------------------------|--|-------------------------------------|--|
| <input type="radio"/> Afghanistan | <input type="radio"/> Djibouti | <input type="radio"/> Libya | <input type="radio"/> Saint Martin |
| <input type="radio"/> Åland Islands | <input type="radio"/> Dominica | <input type="radio"/> Liechtenstein | <input type="radio"/> Saint Pierre and Miquelon |
| <input type="radio"/> Albania | <input type="radio"/> Dominican Republic | <input type="radio"/> Lithuania | <input type="radio"/> Saint Vincent and the Grenadines |
| <input type="radio"/> Algeria | <input type="radio"/> Ecuador | <input type="radio"/> Luxembourg | <input type="radio"/> Samoa |
| <input type="radio"/> American Samoa | <input type="radio"/> Egypt | <input type="radio"/> Macau | <input type="radio"/> San Marino |
| <input type="radio"/> Andorra | <input type="radio"/> El Salvador | <input type="radio"/> Madagascar | <input type="radio"/> São Tomé and Príncipe |

- Angola
- Anguilla
- Antarctica
- Antigua and Barbuda
- Argentina
- Armenia
- Aruba
- Australia
- Austria
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bonaire Saint Eustatius and Saba
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
- Brunei
- Bulgaria
- Burkina Faso
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- French Southern and Antarctic Lands
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Honduras
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar /Burma
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia and the South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Svalbard and Jan Mayen
- Sweden
- Switzerland
- Syria
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Gambia
- Timor-Leste
- Togo
- Tokelau

- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Clipperton
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
- Cook Islands
- Costa Rica
- Côte d'Ivoire
- Croatia
- Cuba
- Curaçao
- Cyprus
- Czechia
- Democratic Republic of the Congo
- Denmark
- Hong Kong
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Isle of Man
- Israel
- Italy
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kosovo
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Northern Mariana Islands
- North Korea
- North Macedonia
- Norway
- Oman
- Pakistan
- Palau
- Palestine
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Pitcairn Islands
- Poland
- Portugal
- Puerto Rico
- Qatar
- Réunion
- Romania
- Russia
- Rwanda
- Saint Barthélemy
- Saint Helena Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks and Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States
- United States Minor Outlying Islands
- Uruguay
- US Virgin Islands
- Uzbekistan
- Vanuatu
- Vatican City
- Venezuela
- Vietnam
- Wallis and Futuna
- Western Sahara
- Yemen
- Zambia
- Zimbabwe

* Organisation size

- Micro (1 to 9 employees)
- Small (10 to 49 employees)

- Medium (50 to 249 employees)
- Large (250 or more)

Transparency register number

255 character(s) maximum

Check if your organisation is on the [transparency register](#). It's a voluntary database for organisations seeking to influence EU decision-making.

859942318143-66

* Publication privacy settings

The Commission will publish the responses to this public consultation. You can choose whether you would like your details to be made public or to remain anonymous.

Anonymous

Only your type of respondent, country of origin and contribution will be published. All other personal details (name, organisation name and size, transparency register number) will not be published.

Public

Your personal details (name, organisation name and size, transparency register number, country of origin) will be published with your contribution.

In the interest of transparency, organisations and associations have been invited to provide the public with relevant information about themselves by registering in Transparency Register and subscribing to its Code of Conduct.

I agree with the [personal data protection provisions](#)

Please indicate if you have work experience in any of these areas

- Cancer care
- Pharmaceutical industry
- Social care sector
- Healthcare sector
- Education sector
- Health/social insurance sector
- Public administration

Are you a healthcare professional?

- Yes
- No

General Questions

1. On a scale from 0 to 10, how present is cancer in your life? (0 is not at all present and 10 very present)

Only values between 1 and 10 are allowed

8

2. What do you think is needed to beat cancer?

- **What do you think citizens can do to help beat cancer?**

600 character(s) maximum

Reducing cancer morbidity and mortality strongly depends on the cooperation of many different actors, including citizens. They should feel responsible for being attentive to the lifestyle they lead, choosing a healthy diet, doing physical activity and avoiding substance abuse related to the development of neoplasms (i.e. tobacco, alcohol, drugs). Discovering cancer in the initial phase can make treatments easier and save lives. Therefore, citizens should not miss the opportunity to participate in primary screening and prevention programs.

- **What do you think health professionals can do to help beat cancer?**

600 character(s) maximum

They should participate in training and education programs that encourage specific updates, study and research in order to strengthen their contribution to prevention and early diagnosis and the spread of health worker awareness of cancer warning signs. Moreover, they should act to encourage the spread of “healthy lifestyles” among patients, focusing on the importance of reducing risk factors. Last but not least, health professionals should feel responsible for providing as complete information as possible to patients on diagnostic procedures and on any therapeutic path to follow.

- **What do you think public authorities/national governments can do to help beat cancer?**

600 character(s) maximum

Public authorities and national governments should define cross-sectoral strategies according to the health in all policies framework. These strategies should not only involve the public system, but also the private sector and the non-profit, which become co-responsible for the success of a prevention plan. Public authorities should develop community-based programmes based on data monitoring (type of cancer; lifestyles of the community members; demographics of the area) and support the shift towards lifestyle choices that reduce the exposure to risk factors.

3. Do you support the idea that the EU should do more to address cancer?

- Yes
- No
- I don't know

In which areas do you think the EU should prioritise its efforts (choose top 3):

at most 3 choice(s)

- Prevention
- Screening and early diagnosis
- Treatment and quality of life of patients and carers
- Life after cancer

- Research and collection of information
- Other
- I don't know

Which actions would you consider most useful in the areas indicated below

- **Prevention**

- Reduce tobacco consumption
- Improve (healthy) diets
- Reduce alcohol consumption
- Increase physical activity
- Reduce obesity
- Increase vaccination against Human papillomaviruses and Hepatitis B
- Avoid excessive exposure to sunlight (including sunbeds)
- Protection from exposure to certain chemicals that can cause cancer
- Other

Please describe

600 character(s) maximum

Implement active policies that allow people to choose better lifestyles such as improving sustainable mobility, access to green areas and community-based information programmes on proper nutrition. These should respond to the urban contexts and to rationing in access to services. A harm reduction strategy for smokers should be defined, including the use of alternative nicotine delivery products such as e-cigs. Regulation needs to balance risks and benefits with the key aim of reducing smoking through the supply of behavioural support and evaluating the impact through monitoring.

- **Screening and early diagnosis**

- Improving the participation to breast, cervical, and colorectal cancer screening
- Extension of screening to other cancer type
- Other

Please describe

600 character(s) maximum

The participation rate in screening services is often unequal amongst the population. Geographic and socio-economic determinants influence participation and access to screening and, thus, early diagnosis. National and local systems should focus on monitoring such inequalities, and set up evidence - based screening campaigns designed to reach the most fragile population subgroups. Particular attention should be placed on the urban environment context, which may increase inequalities in access to health services, and on awareness and disclosure campaigns.

- **Treatment and quality of life of patients and carers**

- Improve access to existing treatments

- Improve access to new innovative treatments
- Better Psychological support inside and outside of health care services
- Improve palliative care
- Improve pain treatment
- Other

Please describe

600 character(s) maximum

Making cancer treatment regimens included in the national clinical practice guidelines accessible to all patients should be the main goal. Providing comprehensive, resource-appropriate and evidence-based cancer service packages requires effective planning and implementation of national cancer control programmes based on epidemiological profiles. Health planners need to be assisted by providing tools to help determine the value of cancer care, and assessment bodies need resources to prioritise the reimbursement of newly licensed medicines based on their incremental clinical benefit.

STEP I: PREVENTION- Preventing cancer by addressing risk factors

Many things related to our lifestyle, and the environment around us may increase or decrease our risk of getting cancer. About 40% of cancer cases could be avoided through prevention measures that have proved to be successful.

Some of the most effective measures are:

- lifestyle changes (healthy diet, physical activity, reduction of obesity, avoidance of tobacco and alcohol consumption),
- vaccination against viruses that cause diseases such as cervical or liver cancer (Human papillomavirus, Hepatitis B),
- avoidance of excessive exposure to sunlight (including sunbeds)
- protection from exposure to certain chemicals that can cause cancer.

More recommendations are available in the [European Code Against Cancer](#), a joint initiative between the European Commission and the World Health Organization's International Agency for Research on Cancer.

4. Do you have enough information about how to prevent cancer?

- Yes
- No
- I don't know

5. Which of the actions below do you think would have the biggest impact on your lifestyle habits (e.g. diet, physical activity, tobacco or alcohol consumption)? (choose top 3)

- Measures on prices (including both taxation and/or incentives)
- Advertising
- Information campaigns
- Legislation
- Other

Please describe

600 character(s) maximum

Healthy lifestyles are not only a matter of willingness but also of opportunity. Legislation and measures on prices can have a direct impact on consumption choices and habits, above all on the most fragile population groups, according to a proactive risk reduction strategy. Behavioural changes can be addressed by promoting less risky alternatives such as vaping or snus for tobacco, which increasing evidence shows results in less exposure to carcinogenic emissions. Official awareness-raising campaigns on smoking are appropriate to inform consumers on responsible habit switches.

STEP II: EARLY DIAGNOSIS - Preventing avoidable cancer cases through cancer screening

An early cancer diagnosis can often significantly increase the chances of successful treatment. The European Union has issued [recommendations](#) for the screening of [breast](#), [cervical](#) and [colorectal](#) cancer.

6. Do you think the EU should extend recommendations for screening of other types of cancer, beyond breast, cervical and colorectal cancer?

- Yes
- No
- I don't know

To which types of cancer in priority?

- Lung cancer
- Gastric cancer
- Prostate cancer
- Ovarian cancer
- Other types of cancer

Other types of cancer

600 character(s) maximum

Pancreatic adenocarcinoma will become the second cause of cancer death in the next two years. This is due to the low detection and awareness of the initial stage symptoms, when early intervention can increase survival chances. A general population screening does not exist (nor is it recommended), but it should be widely and equally available for the more at-risk categories. Information campaigns about risk factors should be promoted regarding both editable (e.g. tobacco is one of the main ones for pancreatic cancer) and non-editable risk factors.

7. What could influence your decision to take part in a cancer screening programme?

- Information about the usefulness of screening and early diagnosis
- Convenience (proximity, ...)
- Cost
- Expertise and skills of healthcare workers
- The safety and quality of the equipment

Other

Please explain

600 character(s) maximum

The awareness of risk factors is crucial in influencing the decision to take part in a screening programme, together with its convenience. The decision to participate is affected by the awareness of being part of a potential risk exposed population group and by the ease of participation (place, time, administrative burden). It is necessary to tackle geographical and social differences that influence ease of participation.

STEP III: TREATMENT - Best available care, treatment and quality of life for all cancer patients

Finding out you have cancer can be quite a shock. It can be difficult in these circumstances to decide how to approach your treatment. And then there is the question of whether you can get the treatment you need, and how much of it will be covered or provided by your health system. As with diagnosis, the best and most effective treatment should be available to all EU citizens. And, whilst our current treatments are indeed effective, new innovative treatments offer us even greater possibilities – yet this innovation can come at a very high cost.

8. What could Europe do to ensure that cancer patients across Europe receive the best available treatment at an affordable price, independently of where they live?

600 character(s) maximum

Strengthening the competences of the ENCR (European Network of Cancer Registries). Cancer registries are the fundamental source of objective cancer data and, thus, are indispensable in evaluating the cancer burden and designing effective cancer control plans. Cancer registration in the EU reveals significant disparities in terms of population coverage, data quality and data output, and the functioning of CRs is subject to personal data protection legislation for public health research. EU-wide registries are desirable to create tailored measures.

9. Do you believe that you know where to find sufficient information about available cancer treatment services where you live?

- Yes
 No

10. Do you consider sufficient written information regarding cancer diagnosis and possible treatments is available to patients ?

- Yes
 No
 I don't know

11. Do you consider adequate support, both inside and outside of the healthcare setting, is available to cancer patients?

- Yes
 No
 I don't know

What additional support do you consider could be made available?

600 character(s) maximum

Much has yet to be done to ensure effective access to psycho-oncological assistance, rehabilitation and support for social reintegration of the patient who lives with cancer or is cured. We support the creation of networks between hospitals and community-based social and health services in order to improve the recognition of needs and thus the inclusion in adequate support and rehabilitation paths.

12. In your experience, do cancer patients receive treatment from a multidisciplinary team of health professionals (oncologists, researchers, psychologists)?

- Yes
- No
- I don't know

13. Do you consider that adequate means are available to help families and friends caring for cancer patients?

- Yes
- No
- I don't know

What additional support do you consider could be made available?

600 character(s) maximum

The socio-economic indirect burden of surviving cancer patients is heavy, both because of the patient's loss of productivity and the strong commitment to assistance that in many cases is required from carers. Carers often have no specific training and have to juggle bureaucratic and organisational obstacles, as well as relations with doctors. We strongly support the implementation of active policies to provide them with economic help, organising specific training and information meetings, easing and improving public home care delivery.

STEP IV: SOCIAL INTEGRATION - Quality of life with and after cancer

The good news is that the number of cancer survivors has increased substantially in the EU over the past decades. However, many of these survivors experience disabilities or long-term side effects of cancer treatment, including emotional distress.

In addition, cancer patients and cancer survivors often face hurdles in the workplace and in matters such as access to employment, insurance, or credit.

14. In your country/region, do cancer survivors receive follow-up and support after treatment?

- Yes
- No
- I don't know

15. Do you consider that cancer survivors experience significant challenges in their daily life?

- Yes
- No
- I don't know

Please indicate in which areas challenges are particularly significant:

- Lack of social rehabilitation, including employment
- Lack of education and training on self-management of your daily life (empowerment of cancer survivors)
- Lack of psychological support to address distress and depression
- Lack of training and support of your informal carers
- Lack of capacity of physicians and nurses to recognise your distress and depression
- Problems linked with medical follow-up, including management of the late effects of treatment
- Problems linked with other diseases (co-morbidity)
- Others

16. Do cancer patients and survivors receive psychosocial support during or after their treatment?

- Yes
- No
- I don't know

17. Do you know or have experience of any particularly good practice in supporting cancer survivors, or do you have any suggestions as to how this could be done?

600 character(s) maximum

A common criticism of traditional models of care is that they are disease focused rather than patient-centred. This also includes the development of targeted measures to support therapeutic adherence, also in terms of healthy lifestyles. Exposure to risk factors continues to play a basic role during and after the treatment. In a patient-centred approach the patient receives education and support on adopting healthy behaviour for the prevention of a recurrence.

GENERAL QUESTIONS:

18. Tell us what a successful cancer plan means to you. 10 years after we implement the plan, what should have improved in the lives of European citizens?

600 character(s) maximum

A successful cancer plan will improve the quality of life of people living with cancer, while reducing its incidence and increasing the overall rate of remission. Since the survival rate in the EU has also been growing, a successful cancer plan must be committed to risk reduction and improving daily assistance.

Achieving this may include continued efforts to decrease smoking rates by preventing the uptake of smoking and promoting cessation through harm reduction plans. A successful plan should be able to provide citizens with independent information on quality of products and alternatives.

19. Provided it is securely managed and in full respect of data protection would you share your personal health data in order to help others and contribute to health improvements (tick all that apply)

- With doctors?
- With researchers?
- With pharmaceutical industry?

20. Have you received information on or been informed about the possibility to take part in clinical trials, including their benefits and risks?

- Yes
- No
- Not applicable

21. How can you (or your organisation) contribute to the EU plan on cancer?

600 character(s) maximum

I-Com will continue to monitor and contribute to the EU decision-making process towards the adoption of the European Cancer Plan through its research, policy and stakeholder engagement activities. As a follow-up to the reply to this consultation, we expect to publish, by this summer, a research paper on best practices for cancer prevention. For this autumn, I-Com is planning a series of policy events on the European Cancer Plan, including a roundtable to present and discuss the main findings of our study.

22. Is there anything else that you would like to add that has not been covered in this consultation?

600 character(s) maximum

Life after cancer - Psycho-social care is considered essential for optimal cancer care, but many patients who could benefit from this are excluded because these needs are often not detected. Guidelines on psycho-social assistance that take into account the specific aspects of individual countries should be developed. Inequalities exist across the EU regarding rehabilitation and reintegration of patients and cancer survivors. Institutions should be made aware of the importance of strategies to improve rehabilitation procedures.

Contact

sante-cancer@ec.europa.eu